



WELCOME

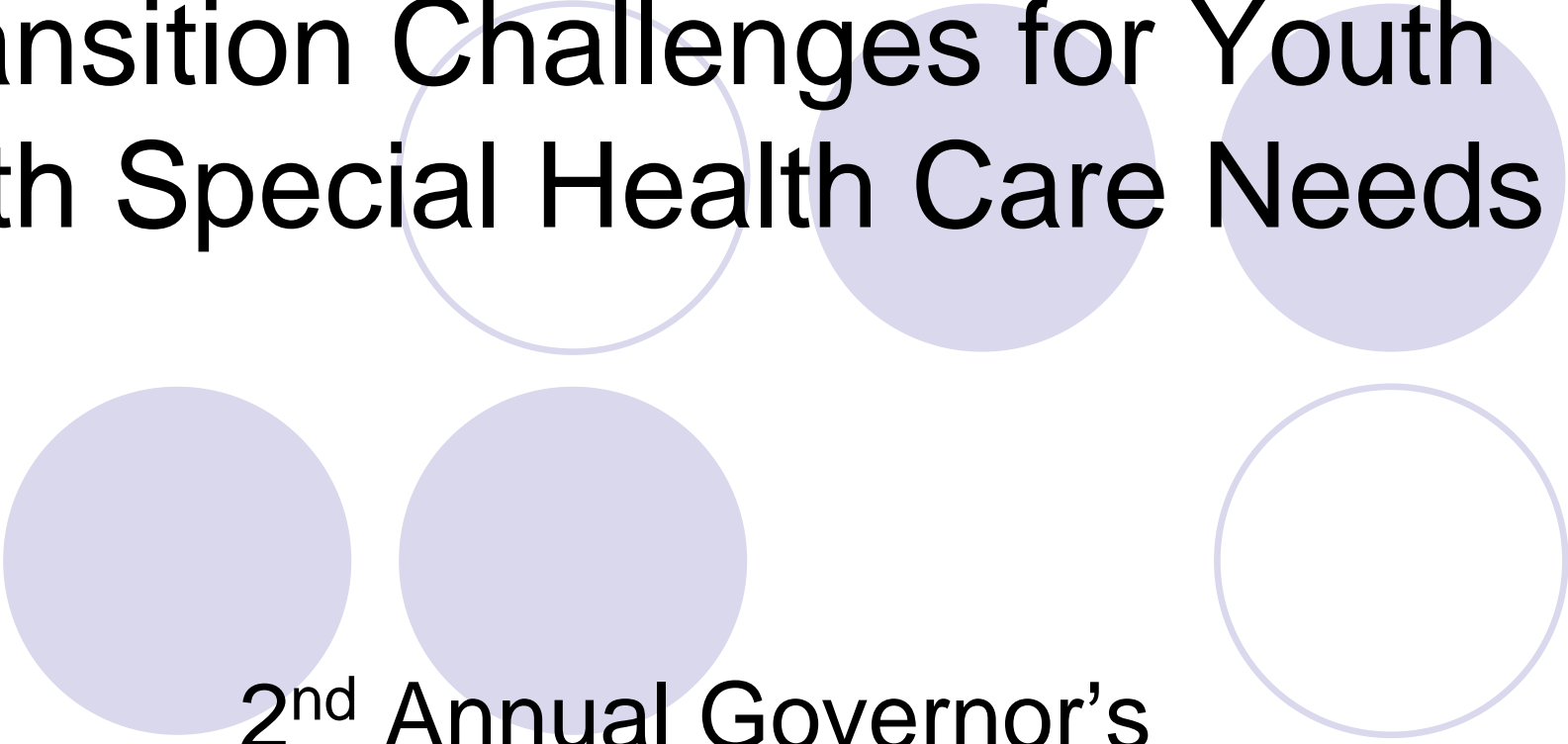
- The first step towards collaboration is networking.

- First assignment

- Introduce yourself to those around you.

- Share why you chose this breakout session.

New Frontiers in Public Health Transition Challenges for Youth with Special Health Care Needs



2nd Annual Governor's
Public Health Conference
May 1, 2007



Objectives

- Increase awareness of transition barriers to achieving Healthy People 2010 and the Maternal and Child Health Bureau's national performance measures.
- Increase understanding of why transition planning is important over a life span to enhance services being provided to CYSHCN.
- Develop detailed action steps to promote youth self-sufficiency and independence for families, youth and providers.



Acronyms & Definitions

- CYSHCN: Children and Youth with Special Health Care Needs.
- Social Capital: defines relationships at the individual, family, community, state and national level that impact the youth's well-being and transition process.

Youth with Special Health Care Needs

Youth with special health care needs are those who have, or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by youth generally.





What is Transition ?

Transition is a continuum of purposeful, planned changes, in various settings, **over a life time** that promotes passage from dependency to self-sufficiency, and independence.

Transition Planning

- Promotes positive self-concept and sense of competence.
- Promotes normal social and emotional development.
- Supports positive self-image and self-reliance.

Adapted from Adolescent Health Transition Project (AHTP) Washington State

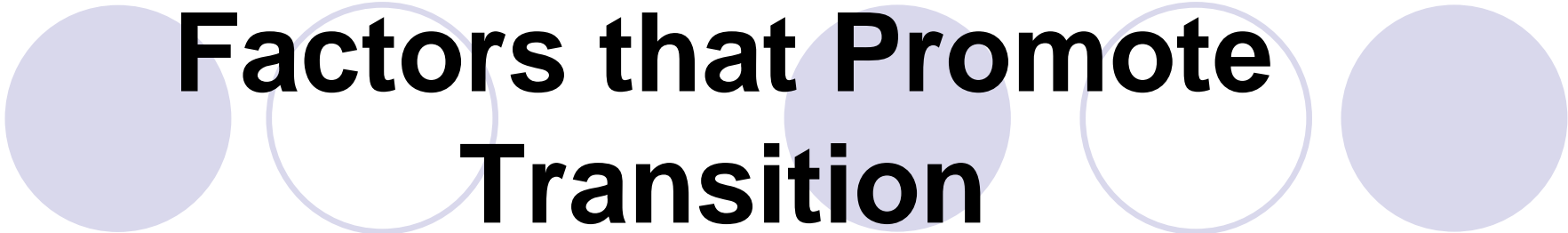


Transition Planning

- Promotes independent living.
- Supports long term planning and life goals.
- Broadens system of interpersonal and social supports.

Adapted from Adolescent Health Transition Project (AHTP) Washington State





Factors that Promote Transition

- Anticipate change - Celebrate transition stages.
- Foster personal and medical independence and creative problem solving that is future focused and flexible.
- Developmental milestones and skill acquisition are learned and mastered.
- A comprehensive plan addresses academic, social and health together, not separately.



Transition Process Begins Early

- Early Intervention has the greatest impact on developmental delays.
- First encounters set the tone for parent engagement and later youth involvement.
- Provide advocacy and anticipatory guidelines (a road map for the journey).

Transition Process

- **Power-over relationships** - professionals exert decision-making control over parents through perceived higher competence.
- **Power-with relationships** - family-centered partnerships.
- **Power-through relationships** - incorporate synergistic decision-making among family members, professionals, friends, and community promoting collective empowerment.

Turnbull, 2000

Power-over relationships

Providers

- Accept family reactions
- Assess family's abilities
- Assure care coordination
- Provide appropriate information in a timely manner

Family

- Shock, grieving process
- Lack knowledge of the disease/disability
- Health care maze and new language
- Rely on others for answers and direction

Power-with relationships (Family-centered model)

Providers

- Share insight and best practices
- Encourages families to ask questions and use new skill sets. Focus on abilities not disabilities
- Utilizes specialist/experts as needed

Family /Youth

- Increased competency
- Have a Medical Home
- Explore new resources, role models
- Family empowers youth

Power-through relationships

Youth to Adult Phase

Providers

- Role evolves from decision maker to consultant with youth
- Co- treatment between primary, specialty and adult services
- Collaborates with school, Voc. Rehab and community

Youth /Family

- Youth has the skills to be self sufficient
- Youth moves from assent to consent role
- Youth owns and directs life objectives and utilizes supports to achieve their potential as an adult



What Are We Striving For?

Healthy People 2010

Overall goal is to increase quality and years of healthy life and eliminate health disparities.

Maternal and Child Health Bureau

All youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work and independence.



Transition Goals

- Youth are empowered and prepared to assume the responsibilities and benefits of adulthood based on their goals.
- Have access to the Social Capital that is prepared and connected to provide seamless service delivery.



Prevention Initiatives

- Seat Belt Laws
- Shaken Baby Prevention Initiative
- Screenings - Newborn, KBH
- Reduced Lead and Mercury Exposure
- Immunizations
- Others



DATA

- One out of 8 babies are born too soon each year increasing the risk for Cerebral Palsy, chronic lung disease, mental retardation, vision and hearing loss.

March of Dimes, 2006
- Chronic physical, mental and emotional disorders continue into adulthood.
- 90% of CSHCN are living into adulthood.

Number and percentage distribution of children in Kansas receiving federally administered SSI payments, by selected characteristics, December 2005

- 7,001 children birth-17 qualified for SSI.
 - 14 y/o ...469
 - 15 y/o... 523
 - 16 y/o... 461
 - 17 y/o... 468

Measurement Tools

- National Survey of Children with Special Health Care Needs (NSCHCN). 2001, (2005 data to be published Fall, 2007)
- School Proficiency in Reading, Math and High School Completion Rates
- IDEA, Indicators 13 & 14
- Others that you monitor?



Data

- People with disabilities are 3 times more likely to live on incomes under \$15,000 annually.
NOD/Harris Survey, 2004
- 30% of 18-29 year olds lack a payment source for needed health care.
Commonwealth Fund, 2005
- 40% of CSHCN vs. 25% of youth without SHCN use the emergency system for care.
KY TEACH Survey, 2003



How is Kansas Doing?

Only 5.2% of Kansas youth receive the necessary services to transition to all aspects of adult life, including adult health care, work and independence.

The nation only ranked 5.8 % on this performance measure.



Social Capital Level of Participation

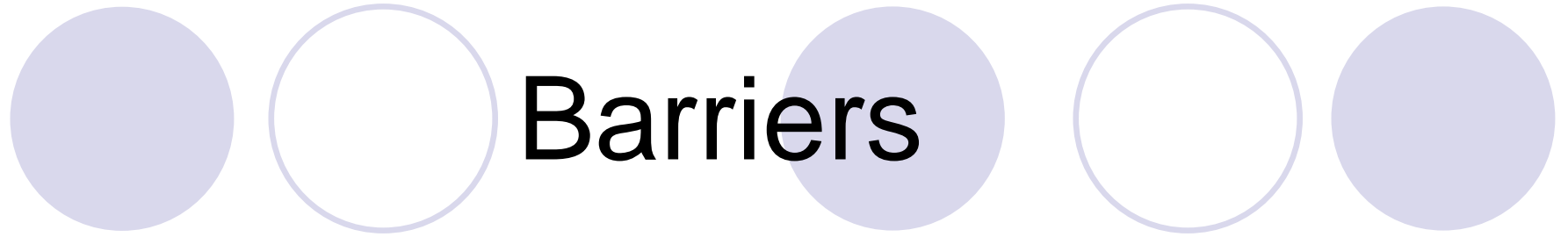
- Networking
- Coordination
- Cooperation
- Collaboration
- Multi-Sector Collaboration

Himmelman, Arthur. *Helping Each Other Help Others:
Principles and Practices of Collaboration*
<http://www.archrespice.org/archfs25.htm#Conclusion>



Social Capital Reality

- In some cases providers and families are unaware of the existence of programs and resources to help.
- Pediatric and adult health care professionals often do not communicate, much less collaborate, to achieve a successful transition of care from one to the other as the child matures.



- Adult providers lack the training to address complex health care needs, learning styles and other accommodations needed by youth with special needs to succeed.

HRTW Phase I Outcome

- Funding allowance and silo funding generally lag behind or restrict access.

Doctors communicate well with each other. (Excellent/ very good).	KS %	US %
2001 NSCSHCN data	36.3	54.4



Effective care coordination was received when needed.	KS %	US %
2001 NSCSHCN data	21.8	39.8

Typically, the health care system does not interact with the education, rehabilitation or insurance systems in planning or facilitating transition.

HRTW Phase I Outcome

The child receives guidance and support in the transition to adulthood.	KS%	US %	Doctors communicate well with other programs (excellent/very well).	KS%	US%
2001 NSCSHCN data	15.8	15.3	2001 NSCSHCN data	32	37.1



Empowering Youth

Success in the classroom, within the community, and on the job requires that young people learn skills early, how to maintain and sustain health and wellness— and to participate in their care decisions.

HRTW

Gaps between Vision and Reality

- Many YSHCN have no experience managing their health care, making medical appointments or even discussing the specifics of their medical conditions.

HRTW Phase I Outcomes

The child receives guidance and support in the transition to adulthood.	KS %	US %
2001 NSCSHCN data	15.8	15.3

Gaps between Vision and Reality

- Many YSHCN want education and employment opportunities, but feel the adults around them either have extremely low expectations of their abilities and future prospects or present barriers to attaining a degree of independence that would be considered normal for a young adult without special health care needs.

2006 YSHCN Survey Results

I would like more health education and information available at school.

- 14.4% Not important
- 10.6% Sort of important
- 37.5% Important
- 18.3% Very important
- 19.2% Extremely important



Disparities

A person with a disability is less likely than their “non disabled peer” to complete high school, attend college, or be employed.

(HRTW, 2000).

The child has received vocational or career training	KS %	US %
2001 NSCSHCN data	19.7	25.5

School Data: Proficiency Rates 2005-06

Student Group	Reading		Math	
	Finding	Goal	Finding	Goal
All Students	80.3%	99.4%	74.7%	99.4%
Students with disabilities	57.4%	98.5%	52.7%	98.6%

KS State Dept. of Education
Report Card-Students with Disabilities

What Youth Need to Know for Successful Health Transition

- Be able to describe signs and symptoms requiring urgent medical attention. Monitor treatments and health parameters.
- Identify emergency health services.
- Understand health promoting behaviors.

Adapted from Peter Scal, Pediatrics 2002

Need to Know for Successful Health Transition (cont.)

- Understand the implications of condition and treatments on sexuality and reproductive health.
- Know about condition-specific support and information organizations.
- Address access to insurance.

Adapted from Scal, *Pediatrics* 2002



Transition Cornerstone

- Accurately synthesized complex medical information that is accessible and available to family members and health providers.

Kelly, Kratz, Bielski, & Rinehart, 2002



2006 YSHCN Survey Results

Do you have a written record of your health treatment, like surgeries, hospital stays, allergies and medication you take?

- 44.5% said yes they did
- 44.5% said no they did not
- 10.9% did not know

2006 YSHCN Survey Results

Do you have an Emergency Care Plan
in place for use in emergencies or disasters?

- 41.3 % said yes
- 42.1 % said no
- 16.5 % said I don't know



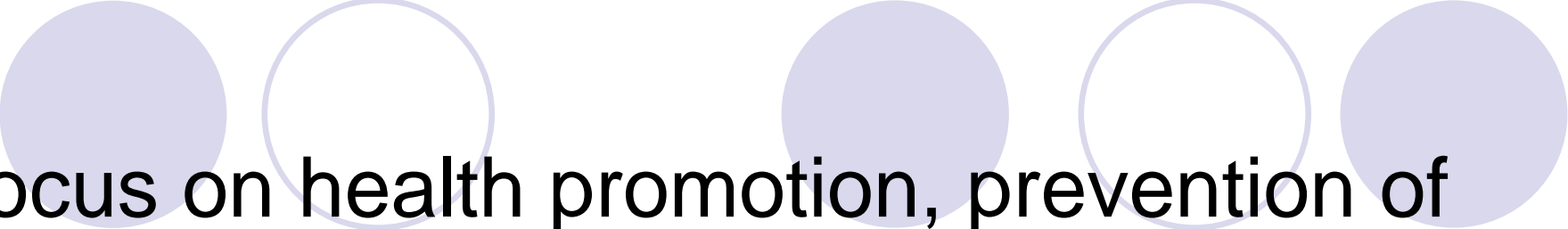
Academic Success depends on

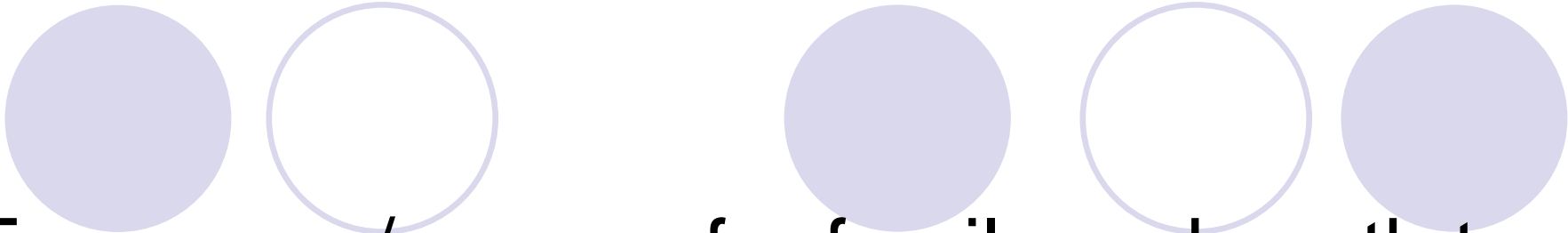
- Program attendance, healthy and ready to learn.
- Practice health promoting practices.
- Collaboration between the youth, family, school and interagency programs that support the youth's adult goals.



Transition Points

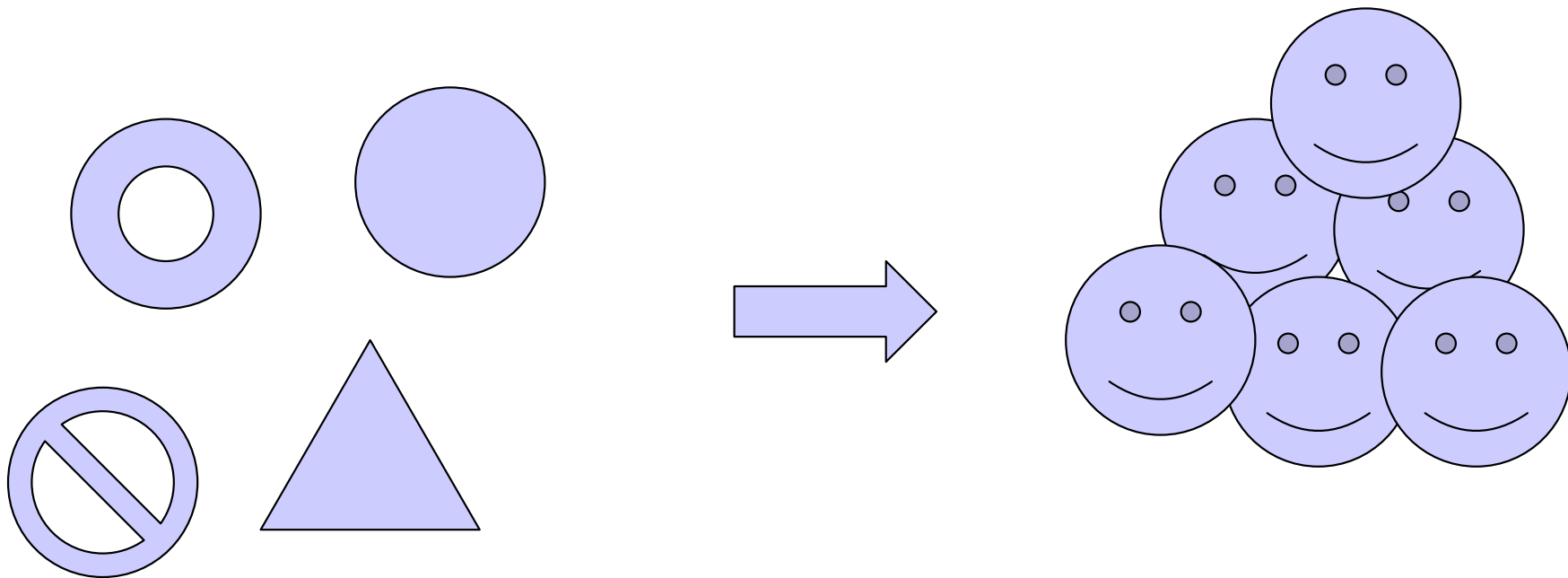
- Discuss life goals and develop a five year action plan that is family/youth directed. Celebrate achievements.
- Define the provider's, parent's and child's/youth's role and responsibilities in the transition process.
- Expect youth to be involved in the health care and educational process and sign documents. (assent to consent).

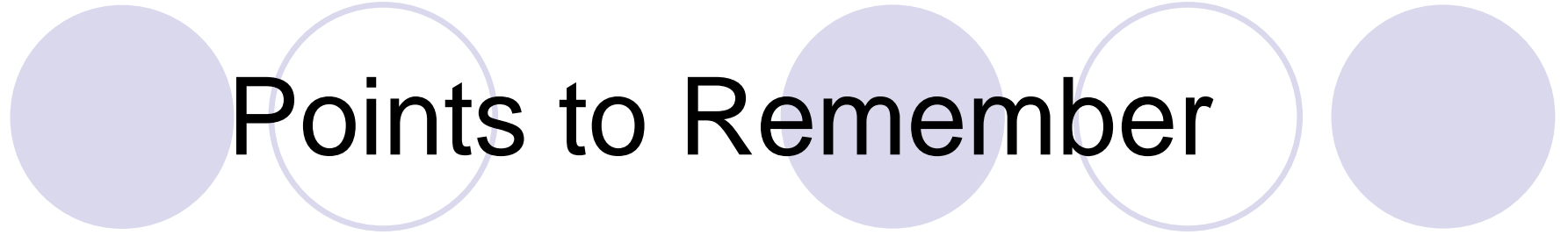
- 
- Focus on health promotion, prevention of secondary disabilities, skill development and prevention of self-destruction.
 - Update portable medical and academic history and outline ongoing interventions needed.
 - Encourage social, recreational and volunteer experiences.

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- Encourage/arrange for family and youth to visit and ‘interview’ potential post secondary education programs and work opportunities.
 - Discuss strategies for selecting an adult health care provider.
 - Be creative, Listen and Listen some more.

Small group discussion

- What will your program do to address transition barriers and build/strengthen social capital for YSHCN?





Points to Remember

- Transition Begins in Childhood.
- Parents and youth must be core team members in decision making.
- Focus on health promotion and normal growth and development to prevent secondary disabilities.


Adapted from AAP Every Child Deserves a Medical Home



Points to Remember cont.

- Refer to developmentally supportive services, early!
- Promote socialization and peer activities.
- Promote self-care and independence.

Adapted from AAP Every Child Deserves a Medical Home



WHAT WE CAN DO

- Barriers are opportunities to redesign the delivery system.
- Silo funding does not preclude creative multi-discipline partnerships to address common barriers.

WHAT WE CAN DO

- **Network.** We learn best from each other.
 - Co-sponsor and attend multi-discipline programs that address common concerns.
 - Submit speaker proposals outside of your professional domain.
 - Include families and youth as experts.



My contact information

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